CCTG PATIENT REPRESENTATIVE PRIORITIES IN CANCER RESEARCH

Workshop Results – April 25, 2024

Abstract

In April 2024, at the Canadian Cancer Trials Group Spring Meeting of Participants, the CCTG Patient Representative Committee members participated in a facilitated session designed to identify the research topics that Committee members view as being most important to cancer patients and caregivers. This document sets out the top 6 identified priorities organized in order of priority along with the methodology used to arrive at this list.

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INTRODUCTION

On April 25, 2024, during a workshop at Spring Meeting, Canadian Cancer Trials Group (CCTG) Patient Representatives participated in a facilitated session designed to identify the research topics that Patient Representatives view as being most important to cancer patients and caregivers. This document sets out the top 6 identified priorities organized in order of priority along with the methodology used to arrive at this list.

METHODOLOGY

A pre-workshop survey (Appendix A) was sent to all Patient Representatives in which they were asked, based on their personal lived cancer experience, to identify potential research priorities or gaps they experienced across the following spectrums:

- Cancer Journey Spectrum

- Cancer Treatment Spectrum

- Cancer Research Spectrum

During the workshop, Patient Representatives were divided into these three "spectrum" groups to review the pre-workshop survey results. Drawing from the survey results and their own experiences, the groups created lists of potential research priorities. Each individual Patient Representative was provided with four coloured stickers so they could "vote" on their highest priority research questions: Red = highest priority; Blue = second priority; Green = third priority; Yellow = fourth priority.

After the workshop, a working group was assigned to consolidate the workshop output. That group consolidated the research priorities, organized them into thematic groups and ranked the potential research priorities using the following methodology. Each research priority was assigned a total score by adding together the different coloured stickers it received based on the following scoring mechanism: Red = 4 points; Blue = 3 points; Green = 2 points; Yellow = 1 point.

To address significant duplication across the "spectrum" groups, all potential research priorities were grouped into research themes and scores were totalled. The final list of top research priorities set out below is based on the research themes that received the highest total scores.

OVERARCHING PRINCIPLES

The following overarching principles should be regarded as paramount when considering the Research Priorities identified by the Patient Representatives:

A) The Research Priorities listed below are disease site agnostic and are intended to encompass all cancers, including those which are considered "rare".

B) Every effort should be made to include patients from historically underrepresented groups in clinical trials. Clinical trial designs should specifically outline how researchers intend to recruit patients from underrepresented groups; and include success criteria and reporting requirements around diversity goals and metrics.

C) All clinical trials should ensure outcomes are focused on having a direct positive impact on patients and include robust Quality of Life patient surveys and reporting.

D) It is critically important that access to clinical trials be expanded and that the time from ideation to operationalization of clinical trials be significantly shortened so that patients can have more ready access to potentially life-saving or life-improving treatments.

RESEARCH PRIORITIES

1. Treatments That Can Completely Cure - Innovative Treatment Options

Patient Representatives recommend that trials focus primarily on innovative therapies, with the goal of finding treatments that can completely cure cancers, by killing both stem cells and growth cells while sparing normal cells. Areas of interest include:

- the use of antibodies, nanoparticles or oncolytic viruses in highly targeted therapies with the potential to selectively attack and destroy specific cancer cells,

- treatments based on oncogenomic analysis,

- CRISPR in vitro gene editing, and

- studies in CAR T-cell, TIL, mRNA, and therapeutic vaccine therapies such as dendritic cell vaccine, and other leading edge research areas.

Some regions in Europe and the US have approved or have trials for novel cancer treatments that are not currently available in Canada. It might be productive to inventory and prioritize these treatments for consideration as study options, thereby

bringing investigational treatments to Canadian patients versus Canadian patients travelling to other countries to receive these treatments.

2. Biomarkers

We see the study of biomarkers and the use of ctDNA as a vital step in the path towards defeating cancer throughout its lifecycle. This includes:

- identification of an individual's predisposition to cancer,

- preventative vaccines,

- early detection,

- personalized treatments, such as therapeutic vaccines and other treatments, and

- surveillance for progression and recurrence during and post treatment.

We also encourage the research and treatment of cancer based on biomarkers rather than location of occurrence, where one or more biomarkers are common to a number of anatomical sites.

3. Use of Technology, Including AI and Digitization

Patient Representatives encourage the exploration of how artificial intelligence can be used to enhance the identification of research opportunities, as well as the analysis of clinical trial results and clinical data that could be used to better patient outcomes or identify patterns for further research. Consideration could also be given to conducting trials with AI objectives; for example, a study of whether AI can be used to improve treatment decisions, or predictions of progression or recurrence.

We also support efforts underway to digitize patient samples and results to optimize their utility.

4. Psychological and Holistic Oncology

As patients, our experience has shown us, and research is establishing, that a patient's mental state and physical well-being can significantly impact their ability to cope with a cancer diagnosis, adhere to treatments, and improve outcomes.   Holistic cancer

treatments can equip patients to develop lifelong wellness habits that enhance long-term quality of life.

Studies could examine whether the use of holistic approaches, including exercise, nutrition, appearance, and mental well-being can augment healing and overall wellness. There are existing web-based tools that have been developed for these purposes.

5. Early Detection

We advocate research in minimally invasive, cost-effective screening tools to detect cancer early in all populations, including individuals under age 40, with quick transition to active treatment.

This includes biomarker-based screening, as noted in section 2 above. It can also include other less-invasive screening methods such as enhanced stool-based tests for colorectal cancer, detection through blood, saliva and/or breath and enhanced imaging, such as low-dose CT scanning.

6. Treatment Optimization

We advocate research studies that aim to optimize treatment dosages and time periods, with the goals of minimizing side effects, patient burden, improving long-term quality of life, while maintaining effective tumour control.

Areas of research could include:

- studies of new, innovative agents that directly target cancer cells while sparing healthy cells, as noted above under innovative treatments,

- studies that aim to improve long-term quality of life, such as replacing radiotherapy, castration, large-scale lymph node dissection and other damaging treatments with less invasive treatments, and

- de-escalation and dose optimization studies.

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    Genitourinary Disease Site – B. Richardson, E. Wanderer
    Gynecology Disease Site – C. Gordon
    Head & Neck Disease Site – B. Richardson
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    Sarcoma Disease Site – J. Heuring
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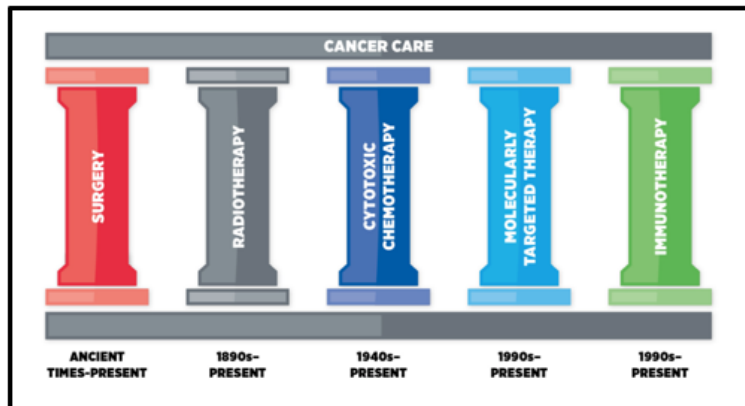   S. Wood
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APPENDIX A – Pre-Workshop Survey

Patient Reps were asked to reflect and think about their specific cancer experiences from three spectrums as identified below and identify any gaps experienced in each section of each spectrum that could in turn be considered for research questions.

1) Cancer Journey Spectrum

2) Cancer Care Spectrum

3) Cancer Research Spectrum